DOCUMENT RESUME

ED 158 485 EC 111 861

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TITLE Preparing Mildly Retarded Young Adults for Integration Into the Community: Observations on Quality of Life.
PUB DATE Jun 78
NOTE 13p.; Paper presented at the World Congress on Future Special Education (First, Stirling, Scotland, June 25 - July 1, 1978)

EDRS PRICE MF-$0.83 HC-$1.67 Plus Postage.
DESCRIPTORS *Adjustment (to Environment); Adults; *Daily Living Skills; Institutes (Training Programs); *Mentally Handicapped; *Normalization (Handicapped); Program Effectiveness; *Quality of Life; Research Projects

ABSTRACT

The study looked at the quality of life of 24 retarded adults who had received a training program designed to teach them independent living skills, help them secure independent living settings, and provide them with followup services in these settings. Physical surroundings, financial conditions, social activities, and marital status of clients were examined. (SBH)

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PREPARING MILDLY RETARDED YOUNG ADULTS FOR INTEGRATION INTO THE COMMUNITY: OBSERVATIONS ON QUALITY OF LIFE

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Paper Presented at the First World Congress
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Sterling, Scotland

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INTRODUCTION

During the past decades, improving the quality of life of retarded persons has been of great concern to parents and professionals in the field of mental retardation. Part of this concern has arisen from the compelling exposes and reports showing the degrading and often inhuman existences experienced by retarded people in institutional settings. These reports have been convincing in their portrayal of life in the typical institutional ward as bleak, isolating and dehumanizing (Wolfensberger, 1974; Braginsky and Braginsky, 1970; Blatt and Kaplan, 1974).

In an attempt to change these conditions, vast efforts have been made toward breaking down the institutional system and providing residential options for retarded people in the community. Policies of deinstitutionalization have been developed across North America, with concurrent efforts at developing community-based residences such as group homes, hostels and supervised apartments (Kugil and Wolfensberger, 1969; Baker, Seltzer and Seltzer, 1974).

Thus, improving the quality of life for retarded people has been almost synonymous with moving retarded people from segregated institutional placements to more integrated community placements, with the tacit assumption that the more integrated and community-based the setting, the better the quality of life. However, does integrated community living for retarded people mean, in fact, good quality of living? What is the quality of life of retarded persons who are living in the community?

To date, little research can be found in the literature that describes the life situations of retarded adults who are in community settings.

Abundant articles and books have been published outlining the ways to provide community residences (Goodfellow, 1974; Shapiro, 1973; Patterson and Byrne, 1973). However, little research is available that actually describes the people's lives in these residences.

Recently, however, two studies were completed in Canada that studied the lives of retarded adults living in the community. Both studies found similar results, indicating that simply residing in the community does not at all guarantee good quality of life. Lambert (1974) studied the living conditions of retarded adults in Ontario. The study focused on the conditions, problems and needs of 454 partially-self-sufficient retarded adults already living in community settings. The following is a quotation summarizing his findings:

> Preparing this report was a depressing, heart-breaking experience. Loneliness, isolation, dependency were but a few of the characteristics of the retarded adults we studied. Many were leading desperate lives, as were the people with whom they were living. Most had been set apart and forgotten by society, since they had been unable to measure up to the stringent and unfair standards society imposed upon them. Yet fully half of those we studied were no more than mildly retarded. Fifty per cent were aged 30 or younger. And three-fourths were living with one or both of their parents.
>
> While three-quarters of the adults we studied rated high in appearance and cleanliness, on all other measures of adaptive behaviour they displayed a tremendous need for assistance. Almost three-fourths of these adults were totally dependent on others to transport them beyond their home. One-quarter to one-third were dependent on others for their shopping and activities of daily living. Only half of the sample satisfied our definition of being integrated into their home. Less than one-third participated in social activities or interacted at an adequate level with other people. And only one quarter of the sample members were working, either full or part-time (P.3).

Further, Elkin (1976) completed a study of mentally retarded adults in Saskatchewan who had moved from institutions to the community. Elkin (1978) stated that he "generally found mentally retarded persons living in extremely impoverished, lonely, isolated circumstances (P.24)." He found that they continued to be segregated from society and that "too frequently community integration for the mentally retarded leads to another form of institutionalization ... segregation in special industries, in group homes, in recreation, in workshops, in education and so on (P.24)." He concluded by saying that "if we are serious about de-institutionalizing services and integrating retarded persons in the community, we must re-examine our ultimate goals and question the assumptions which permit us to accept poverty, loneliness, and isolation for retarded and other disadvantaged persons (P.25)."

Both Lambert and Elkin, then, found that retarded adults living in the community continued to lead lives of boredom, isolation and rejection. However, in neither of these studies were the respondents receiving systematic support from a service agency. Would these findings also hold true for retarded adults who are receiving services specifically designed to help them in these living situations?

In the present study, we looked at the quality of life of retarded persons who had received a training programme specifically designed to teach them independent living skills, help them secure independent living settings and provide them with follow-up services in these settings.

The training programme was funded by a Canadian Government Grant and was under the auspices of a service agency for the mentally retarded in Montreal.

METHOD

For the purpose of this study, quality of life was defined using the principle of normalization. Wolfensberger's (1975) definition of normalization was used:

> Using culturally normative means to offer a person life conditions at least as good as the average citizens, and to as much as possible, support or enhance his appearance, behavior, experiences, status and reputation.*

The quality of life of a mentally retarded person was considered to be acceptable if the two dimensions described in Wolfensberger's definition were met. That is:

(1) if the subject's life conditions were at least as good as that of the average citizen.

(2) if the subject was in a situation that supported or enhanced his appearance, behavior, experiences, status and/or reputation.

Assessments were made by conducting an interview with each person in his home. An interview questionnaire of approximately an hour's duration was developed that obtained data descriptive of the individual's physical surroundings, financial conditions, social activities, and marital status. After obtaining data on these aspects of the subject's lives, judgements were made regarding quality of life using the criteria above.

Of the thirty-seven clients who had completed the training program, twenty-four interviews were completed and these interviews form the basis of this report. These 24 respondents will be referred to as the research group. The average age of the research group was 27.2 years with age ranging from 22 to 44 years. The mean IQ for the group was 64.3; IQ

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*This definition was provided by Wolfensberger in PASS (Program Analysis of Service Systems) Training Workshops, Syracuse, New York.

ranged from 46 to 85. Nine respondents were male and 15 were female. Only six of the twenty-four respondents had some type of experience in an institution for the mentally retarded.

At the time of the interview, members of the research group had been in some form of independent living setting for an average period of 11 months. Five members had their own apartments, 15 were sharing apartments and 4 were living in an unsupervised group home.

RESULTS

Physical Surroundings

Each household was checked for the presence of a package of "survival items" consisting of a fridge, stove, eating utensils, table and chairs and a bed. All 24 members of the research group had the complete set of survival items. Each household was then checked for the presence of a second package of items consisting of a radio, television, record player, substantial dining room and living room furniture. All respondents had a radio, 23 had TV sets, 22 had record players, 18 had substantial dining room furniture and 16 had substantial living room furniture.

Approximately 25% of all items present in the various households were bought by the respondents themselves. The vast majority of items either came with the accommodation or were provided by someone other than the respondent - usually the parents.

Financial Conditions

8 members of the research group were working at the time of our interview. In the Province of Quebec the minimum wage is $3.27 an hour. Using the minimum wage as a guideline, 6 respondents were earning salaries

slightly above the minimum wage and 2 were at minimum wage. In addition, 2 respondents were drawing unemployment.

Of the remaining 14 respondents, 12 received the major part of their income from welfare. Welfare payments amounted to approximately $250.00 a month for these respondents. Only one respondent received regular income from a family source.

All but one of the unemployed group indicated that they wanted to find employment. Job expectations were somewhat lower as only half of those unemployed expected to find a job in the immediate future. Somewhat surprisingly, respondents seemed to be managing on what appeared to be a very limited income. When asked if they had enough money to live on, seventeen responded affirmatively, only seven responded negatively.

The respondents had obviously received considerable training in financial management. Twenty-two of 24 respondents had some type of bank account at the time of the interview. Seven respondents had both chequing and savings accounts. The median amount of savings for the group was $500.00 (data based on 14 clients). Only four respondents indicated that they were having difficulties in the area of financial management. These difficulties appear to be in the area of "being easy prey" for unscrupulous salesmen rather than with the mechanics of managing a bank account.

Social Activities

Birenbaum and Re (1977) in their longitudinal study of mentally retarded adults resettled in the community presented their subjects with a list of 14 activities and/or places they might go to in the community. This list of items was considered "to represent some of the conventional types of behavior adults in the urban environment might engage in while

searching for diversions, companionship or entertainment (P.9)." We presented our research group with the same list of activities. The results indicated that our respondents engaged in substantially more activities both alone and with friends than did the participants in the Birenbaum and Re study. As well, our respondents depended significantly less on the companionship of counsellors than did the Birenbaum and Re subjects.

Respondents were asked to list all their friends. The average number of friends listed was 10. Interestingly, when asked how many of these friends were also members of the organization responsible for the retarded, a mean number of 8 was given. Thus 80% of reported friends are affiliated in some way with the agency for the mentally retarded. On the average, respondents reported seeing most of their friends during the week preceding the interview. This indicates an active social life in terms of personal contacts, but one where the personal contacts are restricted to interaction within a sub-culture.

Another dimension of independent living was obtained by asking respondents if they had taken any trips outside the city of Montreal since beginning independent living. Their responses indicate that 14 of 24 had taken at least one trip while 7 respondents took at least 2 such trips.

Further, respondents were asked if they had been in contact with the law. Eleven of the 24 respondents had some contact with the law. Most of these were minor contacts, however, the most serious offence being a charge of shoplifting against one respondent.

Finally, respondents were asked to indicate that area which was giving them the most difficulty since beginning independent living. Most responses to this question fell into the category of "getting along with people."

Marital Status

Two members of the research group were married although only one was living with her spouse. The spouses were not members of the research group - one was mentally retarded and one was not. Six members of the research group were cohabiting at the time of the interview. In total, 33% of the research group were involved in some form of living with members of the opposite sex.

Fifteen members of the research group were asked about their long term plans regarding marriage, cohabitation, and children. 70% of those asked expected to live with a member of the opposite sex and 85% did not rule out the possibility of children. Twelve of the fifteen respondents answered the question "Do you know how to prevent having children?" Two respondents were unable to articulate any method of birth prevention, 9 respondents knew at least one method, while only one respondent could express more than two methods of birth prevention.

DISCUSSION

In trying to make judgements regarding the individual's quality of life based on the results given above, it is clear that one cannot say overall that the quality is either "acceptable" or "not acceptable," according to our criteria. Rather, varying dimensions of the respondent's lives have varying degrees of quality.

We can see that in the respondent's living conditions, for example, we find residential settings that are both "as good as the average

citizen's" as well as "enhancing and supporting of the person's experiences, status, and reputation". Most of the apartments were well integrated in the community, in typical middle-class neighborhoods. They were well equipped with the possessions required for basic living as well as the majority of possessions that were typical of most Canadian households as reported in Statistics Canada.

We can also see the respondents' quality of life as acceptable when we look at their use of community resources. They, like the typical citizens, use typical community facilities such as stores, movies, restaurants, etc.

These positive findings, however, must be viewed in light of the middle-class backgrounds of most of the research group. Respondents received considerable family support in the form of household furnishings and reported frequent family contacts. Thirty-eight per cent of the respondents reported meeting their parents at least once a week while almost 70 per cent contacted their parents at least once a month. One might ask what will heppen to these people when their parents are deceased. Only one-third of the research group was employed. This is far from acceptable if one is to employ our definition of quality of life. Although the majority of respondents felt that they had enough money to live on, one might be apprehensive about the long term financial resources of many members of the research group.

Further, in analysing the respondents' patterns of social interaction, we see an extremely important phenomenon at work. The research group was found to exist as a cohesive sub-culture, comprised of individuals

who have all been a part of the service agency. Except for contact with family members, virtually all planned contacts were made with other members of the agency, especially members of the research group.

Another area of major concern relates to the child rearing potential of mildly retarded adults. What are the consequences of mildly retarded couples having families - for the couple; the children; society? If the expectations of our respondents are fulfilled, these questions will soon have to be answered.

In conclusion, we feel that the results of this experiment are promising in relation to the goals of normalization. The difficulties observed are a challenge to those undertaking training programs and indicate the need for well planned long term follow-up programs. In addition, as pointed out by Elkin (1976), there is only so much that can be done in the area of training the individual for integration. Beyond this point progress can occur only as a result of a change in society. To this end, in the Province of Quebec legislation has been proposed that would make it mandatory for all employers of over 50 people to employ at least one handicapped person. Interestingly, this legislation is not being well received by handicapped people in Quebec. The appropriateness of this particular legislation is debatable. However, it does represent an increased concern for the aspirations of the handicapped on the part of society.

Finally, I would like to leave you with a response that particularly impressed us when conducting this research, and supports the current trend toward helping retarded people establish themselves in independent community settings. When asked, "What is the best thing that happened to you since beginning independent living?" the majority replied, "Just being on our own; making our own decisions."

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